

Impact of Cancer on Work and Education Among Adolescent and Young Adult Cancer Survivors

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ABSTRACT

Purpose

To examine the impact of cancer on work and education in a sample of adolescent and young adult (AYA) patients with cancer.

Patients and Methods

By using the Adolescent and Young Adult Health Outcomes and Patient Experience Study (AYA HOPE)—a cohort of 463 recently diagnosed patients age 15 to 39 years with germ cell cancer, Hodgkin's lymphoma, non-Hodgkin's lymphoma, sarcoma, and acute lymphocytic leukemia from participating Surveillance, Epidemiology, and End Results (SEER) cancer registries—we evaluated factors associated with return to work/school after cancer diagnosis, a belief that cancer had a negative impact on plans for work/school, and reported problems with work/school after diagnosis by using descriptive statistics, χ^2 tests, and multivariate logistic regression.

Results

More than 72% (282 of 388) of patients working or in school full-time before diagnosis had returned to full-time work or school 15 to 35 months postdiagnosis compared with 34% (14 of 41) of previously part-time workers/students, 7% (one of 14) of homemakers, and 25% (five of 20) of unemployed/disabled patients ($P < .001$). Among full-time workers/students before diagnosis, patients who were uninsured (odds ratio [OR], 0.21; 95% CI, 0.07 to 0.67; no insurance v employer/school-sponsored insurance) or quit working directly after diagnosis (OR, 0.15; 95% CI, 0.06 to 0.37; quit v no change) were least likely to return. Very intensive cancer treatment and quitting work/school were associated with a belief that cancer negatively influenced plans for work/school. Finally, more than 50% of full-time workers/students reported problems with work/studies after diagnosis.

Conclusion

Although most AYA patients with cancer return to work after cancer, treatment intensity, not having insurance, and quitting work/school directly after diagnosis can influence work/educational outcomes. Future research should investigate underlying causes for these differences and best practices for effective transition of these cancer survivors to the workplace/school after treatment.

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INTRODUCTION

Adolescent and young adult (AYA) cancer survivors age 15 to 39 years are faced with a unique set of challenges after diagnosis, including the ability to maintain their work and educational goals during a highly transitional time.^{1,2} Work and education provide survivors with a sense of identity, income, and frequently health insurance for needed treatment and follow-up care.³⁻¹⁰ The ability to return to or maintain occupational and educational pursuits after a cancer diagnosis has been demonstrated to improve the quality of life of patients with cancer, reducing social isolation and increasing self-esteem.^{3,11-13} However, studies in other populations

have demonstrated that returning to work or school can be significantly influenced by a patient's treatment, age at diagnosis, education, or underinsurance, which may all contribute to inadequate assessment of patients' cancer needs.^{4,5,14,15} Understanding how these factors contribute to work and educational outcomes after cancer will play a significant role in the future development of effective survivorship programs in the United States.

Although several studies^{5,14-23} have evaluated factors associated with work and educational outcomes after cancer diagnoses in childhood and older adult populations, few studies have expanded this examination to include recently diagnosed young adult (ie, 18- to 39-year-old) patients. With more

than 500,000 AYA cancer survivors in the United States today,²⁴ identifying ways to reduce disruptions in work and education as survivors transition out of treatment with a chronic disease²⁵ is imperative for reducing the burden of disease on this population, particularly as these individuals balance completing their education with entering into early stages of their career. To identify social and treatment factors associated with changes in work and education after cancer diagnosis in AYA patients, we analyzed data from the National Cancer Institute's (NCI's) Adolescent and Young Adult Health Outcomes and Patient Experience (AYA HOPE) Study. We examined factors associated with a return to full-time employment or school after cancer diagnosis, a belief that cancer had a negative impact on an individual's work or educational plans, and reported problems with work/studies, focusing our analysis on full-time workers/students at diagnosis.

PATIENTS AND METHODS

Data and Patients

The AYA Hope Study²⁶ is an observational cohort study fielded in 2008 to examine factors associated with self-reported outcomes, including quality of life, work and educational status, the perceived impact of cancer, and receipt of high-quality cancer treatment in the community setting. Sampling methodology, survey design, and characteristics of nonrespondents have been previously reported.²⁶ In brief, after obtaining institutional review board approval, we identified patients from seven population-based Surveillance, Epidemiology and End-Results (SEER) cancer registries, including Detroit, Seattle/Puget Sound, Los Angeles County, San Francisco/Oakland, Greater California, Iowa, and Louisiana.²⁷ Eligible patients included those who were (1) diagnosed between July 1, 2007, and October 31, 2008, with primary germ cell cancer, non-Hodgkin's lymphoma, Hodgkin's lymphoma, acute lymphocytic leukemia, Ewing sarcoma, osteosarcoma, or rhabdomyosarcoma; (2) were 15 to 39 years of age at diagnosis; (3) were residents of a participating SEER area at diagnosis; and (4) were able to read English. The initial survey and release forms for medical records were mailed to eligible patients ($n = 1,208$) 6 to 14 months after diagnosis to allow for completion of initial therapy.²⁶ The self-administered patient survey queried participants about their health status and symptoms 6 to 14 months after diagnosis, the impact of cancer, quality of life, information and service needs, health care delivery, and reasons for nonparticipation in clinical trials.²⁸ A follow-up survey was administered 15 to 35 months after diagnosis to examine changes in psychosocial, work, and quality-of-life outcomes from the initial survey. A further description of survey development and validation appears in the Appendix (online only). A total of 524 patients completed the initial survey, resulting in a response rate of 43.4%; 88.7% of these patients ($n = 465$) completed the follow-up survey; two patients were excluded because of unknown employment/school status before diagnosis for a final study cohort of 463 patients.²⁶

Measures

Medical records from facilities listed on patient's health care provider form were abstracted to obtain tumor characteristics, staging, comorbidities, therapy provided, and selected provider characteristics. Tumor staging and initial treatment were classified on the basis of combined SEER registry information and medical record abstraction. Reported cancer type, stage, and treatment were grouped into a treatment intensity variable on the basis of a previously validated methodology because these individual constructs may not fully capture the potentially synergistic effect of these factors.²⁹ A comorbidity score was created from the initial hospitalization record on the basis of previously reported methodology for this age group.³⁰

Additional demographic and occupational information was collected from combined SEER registry data (age at diagnosis, marital status) and the initial AYA HOPE survey (race/ethnicity, education, how insurance was provided before diagnosis, and changes in work/school directly after diagnosis). Having a major source of support (yes/no) was identified on the basis of any

response in the initial survey that the respondent had major support from a family member, significant other, or friend.

Outcomes

Full-time work or school participation 15 to 35 months after diagnosis was identified in the follow-up survey by asking "What is your current school or employment status?" Patients could indicate part-time student, full-time student, working part-time, working full-time, unemployed/disabled, or full-time homemaker. Responses were categorized as participation in full-time work or school versus neither of these (yes/no).

The belief that cancer had a negative impact on work/educational plans 15 to 35 months after diagnosis was assessed in the follow-up survey by asking respondents to "Indicate what kind of impact your cancer has had on . . . plans for education . . . for work." Responses of "somewhat negative" or "very negative" impact were classified as "yes"; "no impact," "not applicable," "somewhat positive," or "very positive" impacts were classified as "no."

Problems with work/studies were identified from the modified Work/School Functioning Scale of the Pediatric Quality of Life Inventory (PedsQL). Primarily used in children and adolescents, this modified PedsQL has robust psychometric properties that have been validated in healthy and chronically ill young adults,³¹ as well as AYA patients with cancer.³² Because we were interested in specific types of problems with work/studies reported in this sample, we report single-item responses from each of the five questions in the Scale (a nonstandard approach) as well as the Scale score to allow for cross-study comparisons. For each item, we dichotomized responses, with a response of "almost always" or "often" compared with all other responses. We then presented unadjusted percentages of patients reporting "always" or "often" for each item.

Statistical Analysis

We used χ^2 tests and multivariate logistic regression to examine associations between patient characteristics and participation in full-time work/education after cancer diagnosis and the belief that cancer had a negative impact on work or educational plans. Model fit was assessed by using C-statistics.³³ Descriptive statistics were used to evaluate the presence of problems with work/school after diagnosis.

Because many factors influencing return to work/school after cancer may be correlated, we conducted several sensitivity analyses to ensure that our findings were not a result of model assumptions. First, we conducted interaction analyses between age, education, marital status, insurance, and change in work/school status directly after diagnosis to evaluate whether the impact of

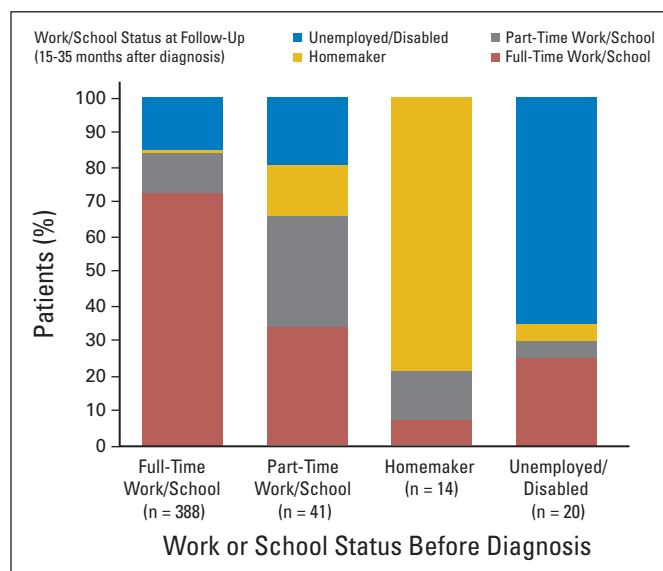


Fig 1. Changes in employment or school status after cancer diagnosis ($n = 463$).

Table 1. Patient Factors Associated With Full-Time Employment/School 15-35 Months After Cancer Diagnosis in Patients Working or in School Full-Time Prior to Diagnosis (n = 388), AYA HOPE Study

Factor		Full-Time Work/School at Follow-Up				P*
		No (n = 106)		Yes (n = 282)		
		No.	%	No.	%	
Demographic						
Age at diagnosis, years					.913	
15-19	16	31.4	35	68.6		
20-24	17	24.6	52	75.4		
25-29	28	29.2	68	70.8		
30-34	24	26.7	66	73.3		
35-39	21	25.6	61	74.4		
Race					.006	
Non-Hispanic white	60	23.4	196	76.6		
Non-Hispanic black	12	46.2	14	53.8		
Hispanic	26	39.4	40	60.6		
Other/unknown	8	20.0	32	80.0		
Sex					.432	
Male	65	26.0	185	74.0		
Female	41	29.7	97	70.3		
Cancer and health-related factors						
Cancer site					.049	
Acute lymphoblastic leukemia	8	53.3	7	46.7		
Germ cell cancer	39	24.4	121	75.6		
Hodgkin's lymphoma	22	21.8	79	78.2		
Non-Hodgkin's lymphoma	32	34.0	62	66.0		
Sarcoma	5	27.8	13	72.2		
Stage at diagnosis					.066	
I/II	56	23.2	185	76.8		
III/IV	37	33.3	74	66.7		
Unknown/unstaged	13	36.1	23	63.9		
Treatment					.004	
Radiation only	13	28.9	32	71.1		
Chemotherapy only	64	34.2	123	65.8		
Radiation and chemotherapy	22	25.0	66	75.0		
Surgery only	6	13.6	38	86.4		
Other/no medical record consent	1	4.2	23	95.8		
Treatment intensity					.039	
Least intensive	6	12.8	41	87.2		
Moderately intensive	64	27.8	166	72.2		
Very intensive	36	32.4	75	67.6		
Comorbidity score					.007	
No medical record consent	2	8.7	21	91.3		
0	62	24.2	194	75.8		
1	25	37.3	42	62.7		
2+	17	40.5	25	59.5		
Social and economic factors						
Had a major source of support					.092	
No	2	10.5	17	89.5		
Yes	104	28.1	265	71.8		
Marital status					.394	
Single/divorced/separated	66	28.9	162	71.1		
Married	40	25.0	120	75.0		
Education					< .001	
High school or less	40	39.6	61	60.3		
Some college/associates degree	48	33.1	97	66.9		
College graduate	16	15.4	88	84.6		
Postgraduate work	2	5.3	36	94.7		
How insurance is provided (mutually exclusive)					< .001	
Self-pay	5	27.8	13	72.2		
No insurance	13	54.2	11	45.8		
Employer/school	28	14.9	160	85.1		
Spouse's employer/school	15	44.1	19	55.9		
Parent	13	24.5	40	75.5		
Public assistance	31	50.8	30	49.2		
Military/TRICARE	1	10.0	9	90.0		

(continued in next column)

Table 1. Patient Factors Associated With Full-Time Employment/School 15-35 Months After Cancer Diagnosis in Patients Working or in School Full-Time Prior to Diagnosis (n = 388), AYA HOPE Study (continued)

Factor		Full-Time Work/School at Follow-Up				P*
		No (n = 106)		Yes (n = 282)		
		No.	%	No.	%	
Employment and survey characteristics						
Change in work/school status directly after diagnosis						< .001
No change		10	11.4	78	88.6	
Took > 2 weeks off		16	12.9	108	87.1	
Changed to part-time work/school		7	18.9	30	81.1	
Quit completely		65	52.4	59	47.6	
Other/unknown		8	53.3	7	46.7	
Time from diagnosis to follow-up survey, months						.563
15-19		13	26.0	38	74.0	
20-24		40	24.2	125	75.8	
25-29		40	30.1	93	69.9	
30-35		13	33.3	26	66.7	

Abbreviation: AYA HOPE, Adolescent and Young Adult Health Outcomes and Patient Experience Study.

*P values indicate unadjusted χ^2 analyses.

these factors varied across other risk factors. In addition, we included each of these variables alone along with cancer and treatment variables to examine whether their impact changed after removing potentially correlated factors. To confirm whether our estimates were influenced by the inclusion of missing values for predictors (< 10% of patients), we repeated all multivariate models excluding those with any missing data. The impact of these factors on our conclusions remained unchanged. All analyses were stratified by work or school status before the cancer diagnosis (full-time work/school, part-time work/school, homemaker, or unemployed/disabled) and were performed by using SAS version 9.2 (SAS Institute, Cary, NC). P values were two-sided, with $P < .05$ considered significant.

RESULTS

Of the 463 patients in the AYA HOPE study who completed initial and follow-up surveys, more than 72% (282 of 388) of patients working or in school full-time before diagnosis had returned full-time 15 to 35 months postdiagnosis compared with 34% (14 of 41) of previously part-time workers/students, 7% (one of 14) of homemakers, and 25% (five of 20) of unemployed/disabled patients ($P < .001$; Fig 1). Overall, only 26.6% (20 of 75) of part-time workers/students, homemakers, and unemployed/disabled patients transitioned to full-time employment or school after diagnosis (Fig 1). Because of this relatively small number, we present data only for patients who were full-time workers/students before diagnosis (Table 1).

Factors Associated With Full-Time Employment or School After Cancer Diagnosis

Unadjusted analyses demonstrated that among full-time workers/students before diagnosis, those diagnosed with acute lymphocytic leukemia and non-Hodgkin's lymphoma were less likely than other cancer types (germ cell cancer, Hodgkin's lymphoma, and sarcoma) to be working/in-school at follow-up (Table 1). Further, non-Hispanic blacks, patients with more intensive

treatment, those treated with chemotherapy only (v all other treatments), those with lower levels of education, and those with non-employer or non-school-sponsored insurance before diagnosis were less likely to return to full-time employment or school at follow-up. Those who quit working immediately after diagnosis and those with higher levels of comorbidities were less likely to return to work/school 15 to 35 months after cancer diagnosis.

After adjusting for patient demographic and treatment factors, the only factors associated with participation in work/school full-time at follow-up were how insurance was provided before diagnosis and changes in work/school status immediately after diagnosis (Table 2). Patients uninsured before diagnosis were significantly less likely to be working full-time at follow-up compared with those whose insurance was provided by their employer or school. Finally, those who quit working/school completely immediately after diagnosis were 85% less likely to return to full-time status at follow-up compared with those who made no change.

Factors Affecting Patients' Beliefs That Cancer Had a Negative Impact on Plans for School or Work

Among full-time workers or students before diagnosis, 34.5% (n = 134) felt that cancer had a negative impact on their plans (Table 3). Unadjusted analyses demonstrated significant differences in the impact of cancer on work or school plans by sex, cancer site, stage at diagnosis, treatment, treatment intensity, and how work/school changed directly after diagnosis. In multivariable analyses, treatment intensity, race/ethnicity, and how work/school changed directly after diagnosis were all significantly associated with the belief that cancer had a negative impact on cancer survivors plans for work or school (Table 4). Patients with very intensive cancer treatment were four times as likely to believe that cancer had a negative impact on plans compared with those receiving least intensive treatments. Further, black patients were more than 75% less likely to believe that their cancer had a negative impact than non-Hispanic white patients. Finally, patients who quit work completely directly after diagnosis were three times more likely to believe cancer had a negative impact than those with no change in status.

Problems With Work or School From Baseline to Follow-Up

A large proportion (> 50%) of all patients working or in school full-time before diagnosis reported some type of problem with work/school both at 6 to 14 months after diagnosis (initial survey) and at 15 to 35 months after diagnosis (follow-up survey; Fig 2). Although the proportion of patients reporting problems with individual work/school items from the PedsQL at least some or all of the time declined from the initial to the follow-up survey, more than 30% of patients working full-time before diagnosis still reported problems with "paying attention" at work/school at follow-up. Further, 15 to 35 months after diagnosis, 53% (n = 205) of all patients reported problems with "forgetting," while 28% (n = 107) reported troubles "keeping up with work or studies." Overall, the average work/school scale score from the PedsQL was 72.7 (standard deviation, 21.5) in this sample.

DISCUSSION

In our study, more than 72% of AYA cancer survivors who were working or in school full-time before diagnosis had returned after 15

Table 2. Multivariate Analyses of Factors Associated With Full-Time Employment/School at Follow-Up Among Full-Time Workers and Students Prior to Diagnosis (n = 388), AYA HOPE Study

Factor	Adjusted Odds Ratio*	95% CI
Age at diagnosis, years		
15-19	Ref	
20-24	1.33	0.46 to 3.90
25-29	1.10	0.34 to 3.54
30-34	0.86	0.24 to 3.03
35-39	0.67	0.19 to 2.42
Race		
Non-Hispanic white	Ref	
Non-Hispanic black	0.71	0.25 to 2.03
Hispanic	0.83	0.41 to 1.68
Other/unknown	1.21	0.46 to 3.17
Sex		
Male	Ref	
Female	0.82	0.45 to 1.51
Treatment intensity		
Least intensive	Ref	
Moderately intensive	0.64	0.22 to 1.83
Very intensive	0.73	0.23 to 2.28
Comorbidity score		
0	Ref	
1	0.88	0.43 to 1.79
2+	0.85	0.36 to 1.99
Had a major source of support		
Yes	Ref	
No	1.73	0.33 to 9.22
Marital status		
Single/divorced/separated	Ref	
Married	0.93	0.45 to 1.93
Education		
High school or less	Ref	
Some college/associates degree	0.87	0.42 to 1.82
College graduate	1.75	0.70 to 4.40
Postgraduate work	4.31	0.78 to 23.8
How insurance is provided (mutually exclusive)		
Employer/school	Ref	
No insurance	0.21	0.07 to 0.67
Self-pay	0.85	0.23 to 3.20
Spouse's employer/school	0.41	0.15 to 1.12
Parent	1.18	0.36 to 3.91
Public assistance	0.61	0.25 to 1.47
Military/TRICARE	2.60	0.23 to 29.8
Change in work/school status directly after diagnosis		
No change	Ref	
Took > 2 weeks off	0.96	0.38 to 2.39
Changed to part-time work/school	0.59	0.18 to 1.92
Quit completely	0.15	0.06 to 0.37
Other/unknown	0.13	0.03 to 0.55
Time from diagnosis to follow-up survey, months		
15-19	Ref	
20-24	0.88	0.36 to 2.12
25-29	0.75	0.31 to 1.82
30-35	0.52	0.16 to 1.67
C-statistic	0.82	

Abbreviations: AYA HOPE, Adolescent and Young Adult Health Outcomes and Patient Experience Study; Ref, reference.

*Each variable adjusted for all other factors listed.

Table 3. Belief That Cancer Had a Negative Impact on Plans for Work or Education Among Full-Time Workers and Students Prior to Diagnosis (n = 388), AYA HOPE Study

Factor		Negative Impact on Plans				P*
		No		Yes		
		(n = 254)		(n = 134)		
Demographic						
Age at diagnosis, years						.377
15-19	31	60.8	20	39.2		
20-24	43	62.3	26	37.7		
25-29	68	70.8	28	29.2		
30-34	54	60.0	36	40.0		
35-39	58	70.7	24	29.3		
Race						.271
Non-Hispanic white	168	63.6	88	36.4		
Non-Hispanic black	21	65.6	5	34.4		
Hispanic	42	80.8	24	19.2		
Other/unknown	23	57.5	17	42.5		
Sex						.037
Male	173	69.2	77	30.8		
Female	81	58.7	57	41.3		
Cancer and health-related factors						
Cancer site						< .001
Acute lymphoblastic leukemia	3	20.0	12	80.0		
Germ cell cancer	128	80.0	32	20.0		
Hodgkin's lymphoma	59	58.4	42	41.6		
Non-Hodgkin's lymphoma	54	57.4	40	42.6		
Sarcoma	10	55.6	8	44.4		
Stage at diagnosis						.002
I/II	173	71.8	68	28.2		
III/IV	64	57.7	47	42.3		
Unknown/unstaged	17	47.2	19	52.8		
Treatment						< .001
Radiation only	42	93.3	3	6.7		
Chemotherapy only	108	57.8	79	42.2		
Radiation and chemotherapy	50	56.8	38	43.2		
Surgery only	36	81.8	8	18.2		
Other/no medical record consent	18	75.0	6	25.0		
Treatment intensity						< .001
Least intensive	39	83.0	8	17.0		
Moderately intensive	161	70.0	69	30.0		
Very intensive	54	46.6	57	51.4		
Comorbidity score						.184
Missing/no medical record consent	16	69.6	7	30.4		
0	175	68.4	81	31.6		
1	41	61.2	26	38.8		
2+	22	52.4	20	47.6		
Social and economic factors						
Had a major source of support						.439
Yes	240	65.0	129	35.0		
No	14	73.7	5	26.3		
Marital status						.254
Single/divorced/separated	144	63.2	84	36.8		
Married	110	68.7	50	31.3		
Education						.106
High school or less	61	60.4	40	39.6		
Some college/associates degree	89	61.4	56	38.6		
College graduate	77	74.0	27	26.0		
Postgraduate work	27	71.1	11	28.9		
How insurance is provided (mutually exclusive)						.156
No insurance	15	62.5	9	37.5		
Self-pay	13	72.2	5	27.8		
Employer/school	133	70.7	55	29.3		
Spouse's employer/school	23	67.6	11	32.4		
Parent	32	60.4	21	39.6		
Public assistance	31	50.8	30	49.2		
Military/TRICARE	7	70.0	3	30.0		

(continued in next column)

Table 3. Belief That Cancer Had a Negative Impact on Plans for Work or Education Among Full-Time Workers and Students Prior to Diagnosis (n = 388), AYA HOPE Study (continued)

Factor	Negative Impact on Plans				P*
	No		Yes		
	(n = 254)		(n = 134)		
	No.	%	No.	%	
Employment and survey factors					
Change in work/school status directly after diagnosis					< .001
No change	71	80.7	17	19.3	
Took > 2 weeks off	87	70.2	37	29.8	
Changed to part-time work/school	25	67.6	12	32.4	
Quit completely	60	48.4	64	51.6	
Other/unknown	11	73.3	4	26.7	
Time from diagnosis to follow-up survey, months					.379
15-19	28	56.0	22	44.0	
20-24	109	66.1	56	33.9	
25-29	92	69.2	41	30.8	
30-35	24	61.5	15	38.5	

Abbreviation: AYA HOPE, Adolescent and Young Adult Health Outcomes and Patient Experience Study.

*P values indicate unadjusted χ^2 analyses.

to 35 months; however, more than 50% continued to report some problems with work/studies on return. Similarly, the majority of patients who were unemployed, disabled, or engaging in only part-time work or school were likely to remain so 15 to 35 months after diagnosis. Among full-time workers/students, uninsured patients and those who quit working directly after diagnosis were least likely to be working/in school at follow-up. Further, very intensive cancer treatments and quitting work directly after diagnosis were associated with an individual's belief that cancer had a negative impact on plans for work/school. Combined, these results add to the growing body of literature examining patterns of work and education after cancer diagnosis that identify segments of the AYA population at risk of being more affected by cancer during the transitional time to older adulthood.

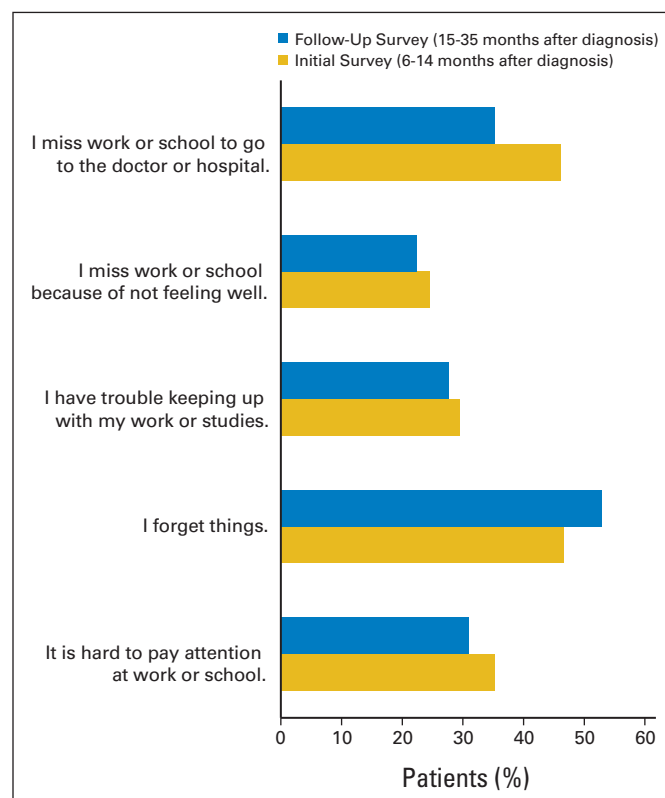
Our estimated rates of return to work among AYA patients with cancer are slightly lower than US national employment rates for this age group³⁴ but are comparable to those of childhood and older adult cancer survivors.^{3,5,14,20-22} In a literature review by Spelten et al,³ the average rate of return to work among cancer survivors was 62% (range, 30% to 93%); however, the review included a wide range of patients with different cancer characteristics. More recently, several studies using the Childhood Cancer Survivor Study (CSSS) have evaluated return to work among adult survivors of childhood cancer, and they find employment rates exceeding 75% among patients with cancers similar to those included in our study.²⁰⁻²² We build on these findings, specifically for young adults, by identifying that a large segment of young cancer survivors will transition back to the work force or school after their cancer diagnosis.

Our study also identified being uninsured and quitting work completely after diagnosis as important risk factors for not returning to full-time employment/school. Although many factors contribute to return to work, many individuals rely on employer-sponsored health insurance to provide needed benefits for themselves and their families. These results suggest that how health insurance is provided, if it is

Table 4. Multivariate Analyses of Factors Associated With a Belief That Cancer Had a Negative Impact on Plans for Work or Education Among Full-Time Workers and Students Prior to Diagnosis (n = 388), AYA HOPE Study

Factor	Adjusted Odds Ratio*	95% CI
Age at diagnosis, years		
15-19	Ref	
20-24	1.35	0.52 to 3.51
25-29	0.98	0.34 to 2.85
30-34	1.93	0.63 to 5.89
35-39	1.18	0.37 to 3.75
Race		
Non-Hispanic white	Ref	
Non-Hispanic black	0.22	0.07 to 0.69
Hispanic	0.85	0.45 to 1.62
Other/unknown	1.07	0.49 to 2.31
Sex		
Male	Ref	
Female	1.37	0.82 to 2.30
Treatment intensity		
Least intensive	Ref	
Moderately intensive	1.65	0.68 to 3.98
Very intensive	4.00	1.56 to 10.26
Comorbidity score		
0	Ref	
1	1.08	0.57 to 2.07
2+	1.65	0.77 to 3.55
Had a major source of support		
Yes	Ref	
No	0.93	0.28 to 3.06
Marital status		
Single/divorced/separated	Ref	
Married	0.95	0.53 to 1.72
Education		
High school or less	Ref	
Some college/associates degree	0.98	0.50 to 1.92
College graduate	0.68	0.30 to 1.55
Postgraduate work	0.87	0.31 to 2.43
How insurance is provided (mutually exclusive)		
Employer/school	Ref	
No insurance	1.44	0.48 to 4.27
Self-pay	0.90	0.26 to 3.06
Spouse's employer/school	0.74	0.28 to 1.90
Parent	1.13	0.41 to 3.14
Public assistance	1.41	0.62 to 3.22
Military/TRICARE	0.89	0.17 to 4.49
Change in work/school status directly after diagnosis		
No change	Ref	
Took > 2 weeks off	1.87	0.92 to 3.78
Changed to part-time work/school	1.78	0.68 to 4.65
Quit completely	3.48	1.62 to 7.48
Other/unknown	1.33	0.32 to 5.49
Time from diagnosis to follow-up survey, months		
15-19	Ref	
20-24	0.70	0.33 to 1.47
25-29	0.60	0.28 to 1.29
30-35	1.42	0.53 to 3.77
C-statistic	0.74	

Abbreviations: AYA HOPE, Adolescent and Young Adult Health Outcomes and Patient Experience Study; Ref, reference.
 *Each variable adjusted for all other factors listed.

**Fig 2.** Reported problems with work and school from baseline to follow-up among full-time workers/students (n = 388).

provided at all, may influence patients to make trade-offs between recovery, work, and health benefits.⁵ Considering that rates of being uninsured peak in adolescence and young adulthood,³¹ finding mechanisms to continue increasing access to insurance and survivorship programs in this population may further aid in the effective transition to work or school after diagnosis. Further, because quitting work/school directly after diagnosis was a significant risk factor for not returning at follow-up, future studies might evaluate reasons for this change to identify potential work/school modifications to prevent dropout from school or the workforce during this transitional time. In addition, these studies might evaluate potential interventions with clinicians and social workers in survivorship programs to balance treatment scheduling with work/school responsibilities or identify evidence-based interventions to minimize treatment adverse effects as a means for preventing work/school dropout.

Apart from returning to work, our study identified higher treatment intensity and quitting work completely after diagnosis as important risk factors for a belief that cancer had a negative impact on plans for work/school. These findings are consistent with previous studies evaluating work outcomes in childhood cancer survivors, for whom treatment regimens were identified as important contributors to not entering the workforce after diagnosis.^{1,2,21} Considering that these AYA patients are at a stage in life when completing education or entering the workforce successfully will greatly influence their future earning and career potential, patients may benefit from the incorporation of resources into the survivorship program that aid in the transition from treatment to occupational or educational pursuits. Thus, future research might focus on effective communication strategies between workers and employers to identify

appropriate work modifications to aid in balancing the demand of work with adverse cancer-related issues, thus preventing patients from quitting work completely.

Our study provides further evidence pointing toward high rates of self-reported problems with work/school on returning. More than 50% of patients in our study who were working full-time before diagnosis reported problems with “forgetting,” and approximately 30% reported troubles “keeping up with work or studies” more than 15 months after diagnosis, indicating that survivors continue to deal with a wide array of issues well after diagnosis. Further, our sample reported work/school functioning scores that were comparable to other AYA and childhood populations with cancer,³¹ but worse than those for healthy young adults.³⁵ Although the reasons behind problems with work/school are often multifactorial, previous studies in other populations have identified associations between chemotoxicity, higher doses of radiation, and long-term adverse treatment effects, including the development of second cancers,³⁶ continued fatigue,³⁶⁻³⁸ physical limitations,^{37,39} and trouble concentrating,⁴⁰ as factors influencing the ability to perform work or school tasks.

Our study provides important data on work/school outcomes after cancer diagnoses in AYAs, but several limitations must be acknowledged. First, our study relied on patient-reported outcomes to evaluate the impact of cancer on work and education. Other financial and educational outcomes would provide additional insight into the monetary impact of cancer, but our study identifies a broad range of concerns and problems that AYA patients with cancer experience after diagnosis. Second, our sample was relatively small, resulting in small cell sizes and wide confidence intervals for some factors. Therefore, we may not have found significant associations for all factors that might influence work/school outcomes. We were also unable to stratify our results by age at diagnosis or workers versus students at diagnosis. Future studies should examine additional factors that may more strongly influence outcomes after diagnosis in these subgroups. Third, the PedsQL has not been extensively validated in those ages 19 to 39. The ability of this instrument to capture the appropriate workplace experiences for this age group should be further evaluated. Fourth, our

study did not distinguish between the type and quality of work performed before and after cancer diagnoses, which may have important socioeconomic implications for these survivors. Finally, our study had a relatively small proportion of nonwhites and did not collect information on all cancer types occurring in the AYA population. As a result, future studies should evaluate how factors identified in our study apply to work/school outcomes in larger, more diverse AYA populations.

Despite these limitations, our study provides further insight into important factors related to a successful return to work/school for AYA patients with cancer. We identified a series of risk factors, including lack of insurance and change in work/school status directly after diagnosis, that significantly influence returning to work after cancer diagnosis. With a growing US population of more than 500,000 AYA cancer survivors, the majority of whom will return to work/school after diagnosis, future research should investigate best practices for effective transition and retention of cancer survivors in the workplace/school after treatment.

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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REFERENCES

- Pang JW, Friedman DL, Whitton JA, et al: Employment status among adult survivors in the Childhood Cancer Survivor Study. *Pediatr Blood Cancer* 50:104-110, 2008
- Langeveld NE, Ubbink MC, Last BF, et al: Educational achievement, employment and living situation in long-term young adult survivors of childhood cancer in the Netherlands. *Psychooncology* 12:213-225, 2003
- Spelten ER, Sprangers MA, Verbeek JH: Factors reported to influence the return to work of cancer survivors: A literature review. *Psychooncology* 11:124-131, 2002
- Bradley CJ, Bednarek HL: Employment patterns of long-term cancer survivors. *Psychooncology* 11:188-198, 2002
- Bradley CJ, Neumark D, Luo Z, et al: Employment and cancer: Findings from a longitudinal study of breast and prostate cancer survivors. *Cancer Invest* 25:47-54, 2007
- Nachreiner NM, Dagher RK, McGovern PM, et al: Successful return to work for cancer survivors. *AAOHN J* 55:290-295, 2007
- Ganz PA: Current issues in cancer rehabilitation. *Cancer* 65:742-751, 1990
- Chirikos TN, Russell-Jacobs A, Cantor AB: Indirect economic effects of long-term breast cancer survival. *Cancer Pract* 10:248-255, 2002
- Hays DM: Adult survivors of childhood cancer. Employment and insurance issues in different age groups. *Cancer* 71:3306-3309, 1993
- Hoffman B: Current issues of cancer survivorship. *Oncology (Williston Park)* 3:85-88, 1989; discussion 89-91, 94-95
- Hakkaart-van Roijen L: Societal perspective on the cost of illness [doctoral thesis]. Erasmus University Rotterdam, Rotterdam, the Netherlands, 1998. <http://repub.eur.nl/res/pub/17166/>
- Barofsky I (ed). *Work and Illness: The Cancer Patient*. New York, NY, Praeger, 1989
- Peteet JR: Cancer and the meaning of work. *Gen Hosp Psychiatry* 22:200-205, 2000
- Earle CC, Chretien Y, Morris C, et al: Employment among survivors of lung cancer and colorectal cancer. *J Clin Oncol* 28:1700-1705, 2010
- Bouknight RR, Bradley CJ, Luo Z: Correlates of return to work for breast cancer survivors. *J Clin Oncol* 24:345-353, 2006
- Roelen CA, Koopmans PC, Schellart AJ, et al: Resuming work after cancer: A prospective study of occupational register data. *J Occup Rehabil* 21:431-440, 2011
- Bonneau J, Lebreton J, Taque S, et al: School performance of childhood cancer survivors: Mind the teenagers! *J Pediatr* 158:135-141, 2011
- Ellenberg L, Liu Q, Gioia G, et al: Neurocognitive status in long-term survivors of childhood CNS malignancies: A report from the Childhood Cancer Survivor Study. *Neuropsychology* 23:705-717, 2009
- Gurney JG, Krull KR, Kadan-Lottick N, et al: Social outcomes in the Childhood Cancer Survivor Study cohort. *J Clin Oncol* 27:2390-2395, 2009
- Kirchhoff AC, Krull KR, Ness KK, et al: Physical, mental, and neurocognitive status and employment outcomes in the childhood cancer survivor study cohort. *Cancer Epidemiol Biomarkers Prev* 20:1838-1849, 2011
- Kirchhoff AC, Krull KR, Ness KK, et al: Occupational outcomes of adult childhood cancer survivors: A report from the childhood cancer survivor study. *Cancer* 117:3033-3044, 2011

22. Kirchhoff AC, Leisenring W, Krull KR, et al: Unemployment among adult survivors of childhood cancer: A report from the childhood cancer survivor study. *Med Care* 48:1015-1025, 2010
23. Kunin-Batson A, Kadan-Lottick N, Zhu L, et al: Predictors of independent living status in adult survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Pediatr Blood Cancer* 57:1197-1203, 2011
24. National Cancer Institute: Cancer Survivorship Research: Estimated U.S. Cancer Prevalence. <http://cancercontrol.cancer.gov/ocs/prevalence/prevalence.html#age>
25. Zebrack B, Bleyer A, Albritton K, et al: Assessing the health care needs of adolescent and young adult cancer patients and survivors. *Cancer* 107:2915-2923, 2006
26. Harlan LC, Lynch CF, Keegan TH, et al: Recruitment and follow-up of adolescent and young adult cancer survivors: The AYA HOPE Study. *J Cancer Surviv* 5:305-314, 2011
27. National Cancer Institute: Surveillance, Epidemiology and End Results (SEER) Program Research Data (1973-2007). 2010. <http://seer.cancer.gov/registries/index.html>
28. National Cancer Institute: Adolescent & Young Adult Health Outcomes & Patient Experience Study. <http://outcomes.cancer.gov/surveys/aya>
29. Werba BE, Hobbie W, Kazak AE, et al: Classifying the intensity of pediatric cancer treatment protocols: The intensity of treatment rating scale 2.0 (ITR-2). *Pediatr Blood Cancer* 48:673-677, 2007
30. Parsons HM, Harlan LC, Seibel NL, et al: Clinical trial participation and time to treatment among adolescent and young adults with cancer: Does age at diagnosis or insurance make a difference? *J Clin Oncol* 29:4045-4053, 2011
31. Varni JW, Limbers CA: The PedsQL 4.0 Generic Core Scales Young Adult Version: Feasibility, reliability and validity in a university student population. *J Health Psychol* 14:611-622, 2009
32. Ewing JE, King MT, Smith NF: Validation of modified forms of the PedsQL generic core scales and cancer module scales for adolescents and young adults (AYA) with cancer or blood disorder. *Qual Life Res* 18:231-244, 2009
33. Peng CY, Lee KL, Ingersoll GM: An introduction to logistic regression analysis and reporting. *J Educ Res* 96:3-14, 2002
34. US Department of Labor: Employment status of the civilian noninstitutional population by age, sex, and race. U.S. Bureau of Labor Statistics, 2012. <http://www.bls.gov/cps/cpsaat03.htm>
35. Adams SH, Newacheck PW, Park MJ, et al: Health insurance across vulnerable ages: Patterns and disparities from adolescence to the early 30s. *Pediatrics* 119:e1033-e1039, 2007
36. Razavi D, Delvaux N, Brédart A, et al: Professional rehabilitation of lymphoma patients: A study of psychosocial factors associated with return to work. *Support Care Cancer* 1:276-278, 1993
37. Satariano WA, DeLorenze GN: The likelihood of returning to work after breast cancer. *Public Health Rep* 111:236-241, 1996
38. Berry DL: Return-to-work experiences of people with cancer. *Oncol Nurs Forum* 20:905-911, 1993
39. de Lima M, Strom SS, Keating M, et al: Implications of potential cure in acute myelogenous leukemia: Development of subsequent cancer and return to work. *Blood* 90:4719-4724, 1997
40. Bloom JR, Hoppe RT, Fobair P, et al: Effects of treatment on the work experiences of long-term survivors of Hodgkin's disease. *J Psychosoc Oncol* 6:65-80, 1988

